Palliative Care for Severely Affected Patients with Multiple Sclerosis: When and Why? Results of a Delphi Survey of Health Care Professionals

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Abstract

Background: Patients severely affected by multiple sclerosis (MS) present with complex symptoms and needs requiring an interdisciplinary care approach.

Objective: Analysis of when and why specialized palliative care integration would be beneficial via examining health care professionals' attitudes.

Design: A two-round online Delphi study and expert workshop were undertaken and analyzed descriptively.

Setting/Subjects: Following an extensive online search, 164 professionals with expertise in treating and caring for severely affected patients with MS were contacted. Professionals included neurologists, urologists, general practitioners, MS nurses, speech therapists, physiotherapists, psychologists, and palliative care physicians. Forty-six consented to participate: 33 of 46 (71.4%) and 15 of 33 (45.5%) experts responded in the first and second round, respectively.

Results: Consensus was reached among all respondents (100%) defining the term "severely affected": 78.8% and 86.7%, respectively, thought that specialized palliative care should begin once the disease has progressed (Expanded Disability Status Scale [EDSS] >6 and nursing care required). When the need exists for communication about disease progression (93.3%), psychological support (93.3%), relatives support (93.3%), and pain medication (86.7%) specialized palliative care should be consulted. Specialized palliative homecare was rated (93.3%) "very important." The workshop documented the paucity of home visits and specialized MS care in nursing homes.

Conclusions: Our results clearly identified specific areas in which palliative care will likely prove to be a valuable asset in the treatment course of MS. This information should serve clinicians, indicating when to consider palliative care services and help further reduce or eliminate uncertainty about how palliative care can be integrated in the course of MS.

Introduction

MULTIPLE SCLEROSIS (MS) is the most common chronic autoimmune inflammatory and demyelinating disease of the central nervous system. A recent study by Leray et al.¹ divided the clinical course of MS into an early and a late phase. The duration of the latter phase was nearly identical among patients regardless of the duration of the first phase. This suggests that MS disability progression in phase 1

probably depends on autoimmune demyelination and can be modified, whereas the second stage probably relates to axonal loss and cannot be causally influenced. Optimizing treatment and care for severely affected patients with MS in this later stage thus presents a challenge. The question then arises as to when and why palliative care can help.

Severely affected people with MS suffer from a variety of symptoms such as fatigue, immobility, physical dysfunctions, intense pain, and/or psychological distress.²⁻⁵ Depressive

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FIG. 1. The Delphi procedure.

symptoms are highly prevalent among patients with MS with a lifetime risk of approximately 50% compared to 10%–15% among the general population. More than half of cases of depression among patients with MS go undiagnosed.⁶ Our research showed that patients with MS are interested in communicating about issues concerning death and dying,^{7,8} especially since the burden of the disease can sometimes produce suicidal ideation⁹ as reflected in alarming rates of euthanasia and assisted suicide for patients with MS.^{10,11} MS may be complicated by cognitive impairment, swallowing, or speech problems. Managing MS requires assistance from a wide range of health care specialists throughout the patient's life. Initial findings indicate that palliative care can be a valuable complementary asset for patients severely affected by MS.^{12,13} However, palliative care is still not currently offered routinely to patients with MS as it is to patients with cancer.¹⁴ Our studies showed that major misunderstandings and a lack of information among health care professionals about the tasks and services of palliative care¹⁵ for MS are still prevalent. A study by Higginson et al.¹³ aimed to develop and evaluate a new palliative care service integrated with existing MS nursing and rehabilitation services for people severely affected by MS. Their study offers the first evidence that patients receiving PC for 12 weeks displayed improvements in five key symptoms compared to deterioration among the control group. These symptoms can be seen as “flags” for when to integrate palliative care into routine MS management, namely to control pain, nausea, vomiting, mouth problems, and sleeping.

Consensus is still needed on further criteria as to when and whether patients would benefit from the addition of specialist palliative care as this remains underinvestigated in Germany. Despite the fact that there are already interventional studies that have tested those indications,¹³ none exists for Germany.

Since health care systems differ greatly,^a it is impossible to simply transfer data from U.K. studies directly to Germany and elsewhere, although the preliminary data invites future MS research. Pilot data need to be obtained for Germany. Our main objective therefore was to identify “when” and “why” PC should be integrated into the treatment of MS by analyzing the views of health care professionals.

Methods

Study design

Two online Delphi rounds were conducted to gain consensus (at least 75%) within the group of health care professionals. The Delphi method is a formal consensus technique whereby the main purpose is to obtain the most reliable consensus of opinion from a group of experts.¹⁷ The method has been widely and effectively used in medical and nursing research and is also common in palliative care.^{18–20} This approach provides the participants in the second round with the results of the first so that they can alter their original assessments if they so desire or stand by their previous opinion. Independent objectivity is ensured because the

^aIn Germany, the provision of health care can be broadly separated into outpatient and inpatient sectors. Outpatient services are largely the responsibility of independent physicians practicing on a freelance basis under contract to the statutory health insurers. Physicians treating patients who are members of the statutory health insurance funds must, by law, be registered with the regional Association of Statutory Health Insurance Physicians (see also Obermann et al.¹⁷). Medical care services are generally classified into three broad categories: curative (e.g., drugs, treatments, and surgeries), restorative (e.g., physical, occupational, and speech therapies), and preventive (e.g., prenatal care, mammograms, and immunizations).

survey questionnaire is anonymous.²¹ Figure 1 offers an overview of this Delphi study design.

Pilot testing. The first version of the questionnaire was developed by the research team based on previous studies^{2,7,15} and pilot tested with six health care professionals (nurse, psychotherapist, neurologist, case manager, physiotherapist, and social worker) to affirm the comprehensibility of the questionnaire and usefulness of the response options. The pilot test resulted in some items being restructured for clarity and modifying the wording of some statements.

Recruitment and participants. Research using the Delphi method relies on participants constituting a panel of experts. A suitable expert was defined for our purposes as someone possessing the relevant knowledge and experience of the topics being investigated.²² Professionals contacted thus included neurologists, urologists, general practitioners, MS nurses, speech therapists, physiotherapists, psychologists, and palliative care physicians with expertise in treating and caring for severely affected patients with MS. Following an extensive online search for participants in the Cologne/Bonn region of Germany, e-mails were sent requesting participation. As many experts as possible were sought because response rates vary greatly, and a 60% response rate has been recognized as the threshold of acceptability, however, "...similar to $p \leq 0.05$ in statistical comparisons, 60% is only a "rule of thumb...".²³ Each Delphi round lasted 4 weeks and two reminders were sent per round according to Dillman's suggestions.²⁴

Ethical approval was granted by the Ethics Commission of the Cologne University Faculty of Medicine (#10-130).

Data analysis. Data were collected via two online questionnaires. Received answers were analyzed descriptively using PASW 18 (SPSS, an IBM Company). Survey identification

numbers were utilized to encode the participants and anonymize the data. Agreement of 75% or more to the given response options: "yes" or "no" defined consensus as set *a priori*.

Workshop. An expert workshop with neurologists ($n=3$), palliative care physicians ($n=2$), psychologists ($n=2$), speech therapists ($n=1$), representatives of the patient organization German Multiple Sclerosis Society ($n=2$), and scientific assistants ($n=2$) was held on June 6, 2012 at the Center for Palliative Care located at the University Hospital of Cologne. Three experts attending also participated in our Delphi survey. After presenting the results of both Delphi rounds to the group, there was an open discussion aimed at identifying areas of consensus, differences in viewpoint and gaps in knowledge with regard to optimal care for severely affected MS patients and the integration of PC for managing MS. Minutes of the workshop were taken and analyzed via global analysis.²⁵

Results

Sample

Of the 164 experts, 46 consented and were e-mailed the link for the online survey (Fig. 2). Thirty-three participants in the first round yielded a response rate of 71.4%; 15 responses were obtained in the second round (45.5%). The distribution of professions can be seen in Table 1.

Participants registered a mean of 14.4 years of experience (standard deviation [SD]=8.518) in treating severely affected patients with MS in the first round, and a mean of 13.3 years (SD=6.904) in the second round. Self-reported estimates of "high" to "rather high" expertise in treating MS reached 60.2% (first round) and 60.0% (second round), with an average of four severely affected patients with MS seen in the 3 months prior. Experience with inpatients averaged 63.6% ($n=21$) and 53.3% ($n=8$), respectively; and with

FIG. 2. Flow of participants in the Delphi survey.

TABLE 1. PROFESSION (MULTIPLE ANSWERS POSSIBLE)

<i>Profession</i>	<i>First round</i> (n=33) % (n)	<i>Second round</i> (n=15) % (n)
Neurology	36 (12)	39 (7)
Palliative care	15 (5)	17 (3)
Nursing care	13 (6)	28 (5)
Physiotherapy	12 (4)	11 (2)
Urology	6 (2)	0 (0)
Psychology	6 (2)	6 (1)
Palliative nursing care	6 (2)	11 (2)
Social work	6 (2)	6 (1)
Multiple sclerosis nurse	3 (1)	6 (1)
Speech therapy	3 (1)	6 (1)
Case management	3 (1)	0 (0)
General medicine	3 (1)	0 (0)

outpatients 78.8% (n=26) and 73.3% (n=11), respectively (multiple answers possible).

Consensus on definition of “severely affected by MS”

What it means to be severely affected by MS was initially defined by the research team (J.S., V.R., M.G., H.G., R.V.) based on previous findings of our own studies^{2,7,15,26} and experience in treating MS patients (H.G., R.V.) and thus used to ensure that all respondents were referring to the same concept of being severely affected by MS when answering the questionnaire:

People affected by MS are severely affected if they have to cope with severe limitations in their lives lived so far. Hereby severe limitations can affect diverse functional systems (i.e.,

motor functions, balance, sensorium, vegetative functions, cognition) and lead to physical (i.e., sexual dysfunction, tetraparesis, severe ataxia) as well as psychic (i.e., depression, dementia) disorders. Such changes often present a huge challenge for (caring) relatives as well.

Consensus for this definition was reached among all respondents in both rounds (100%).

Deficits in care

A number of deficits in current care were identified (Table 2).

Integration of palliative care in MS

Health care professionals were asked how important they considered the integration of palliative care in the course of MS (Table 3).

One expert in the workshop offered the idea that general practitioners (GPs) and/or private neurologists could have a palliative care expert present during consultations. Both patients and physicians might benefit from “new” input and knowledge, perhaps diminishing insecurities surrounding palliative care beforehand for physicians, and especially patients and family.

One physician suggested establishing a network for palliative care and MS in which both health care professionals and patients can seek MS-specialized personnel and/or work on ideas for future (scientific and clinical) multicenter studies.

It was generally agreed that knowledge gaps exist with respect to the services palliative care provides. Specialized palliative homecare teams were unknown to some of the experts, and once informed they were surprised to hear that they were easy to utilize.

TABLE 2. DEFICITS IN CARE

Delphi questionnaire	Considering your experience: which symptoms and problems are insufficiently met by current care provision?	<i>First round</i> (n=33)	<i>Second round</i> (n=15)
		<i>Yes</i>	<i>Yes</i>
		% (n)	% (n)
Delphi questionnaire	Changes in personality	72.7 (24)	80.0 (12)^a
	Cognitive disorders	57.6 (19)	86.7 (13)
	Depression	51.5 (17)	80.0 (12)
	Increasing dependency	63.6 (21)	86.7 (13)
	Role changes within the family	66.7 (22)	80.0 (12)
	Social isolation	66.7 (22)	86.7 (13)
	In need of care	66.7 (22)	73.3 (11)
Expert Workshop (n=12)	Lack of home visits by neurologists, psychologists, co-therapists		
	Lack of MS specific-knowledge by institutions, i.e., nursing homes		
	Lack of specialized nursing care homes for MS patients (i.e., MS patients still being cared for in nursing care homes for the elderly and/or people with dementia)		
	Psychotherapists and/or psychiatrists have only little expertise in MS/neurology		
	PC services often lack specific MS/neurologic knowledge and experience		

^aItems attaining consensus (at least 75%) in bold.
MS, multiple sclerosis.

TABLE 3. INTEGRATION OF PALLIATIVE CARE IN MULTIPLE SCLEROSIS

Importance of palliative care integration in MS	First round (n=33)			Second round (n=15)		
	% (n)			% (n)		
Important	69.7 (23)			93.4 (14)		
Rather unimportant	24.2 (8)			6.7 (1)		
Don't know	6.1 (2)			0.0 (0)		
Total	100.0 (33)			100.0 (15)		
Best time to integrate palliative care in MS (Delphi questionnaire)	First round			Second round		
	Yes	No	Don't know	Yes	No	Don't know
	At diagnosis	81.8 (27)^a	12.1 (4)	0.0 (0)	93.3 (14)	6.7 (1)
	Relapse	72.7 (24)	15.2 (5)	6.7 (1)	80.0 (12)	13.3 (2)
	Depression	72.7 (24)	6.1 (2)	6.7 (1)	80.0 (12)	13.3 (2)
	Progressed MS (EDSS > 6 and nursing care required)	78.8 (26)	18.2 (6)	3.0 (1)	86.7 (13)	6.7 (1)
Best time to integrate palliative care in MS (Expert Workshop)	General palliative care			Specialized palliative care		
	When starting mitoxantrone (immunosuppressant) and/or EDSS ≥ 6.0 and/or when having a relapse and/or when having to apply for assistive technology / aids for the first time in the disease trajectory			EDSS ≥ 8.0 and/or two symptoms on the HOPE Scale ¹⁴ (0–3) ^b with the score of 3 and/or decreasing cruising radius and/or the need for moving into a nursing care home or admission to a hospital		
Tasks in which palliative care should support primary healthcare	First round			Second round		
	Yes	No		Yes	No	
	Support for relatives	71.9 (23)	18.8 (6)	93.3 (14)^a	6.7 (1)	
	Psychological support	71.9 (23)	15.6 (5)	93.3 (14)	6.7 (1)	
	Communication on the progression of disease	56.3 (18)	31.3 (10)	93.3 (14)	6.7 (1)	
	Pain medication	71.9 (23)	21.9 (7)	86.7 (13)	6.7 (1)	
	Outpatient care	53.1 (17)	40.6 (13)	86.7 (13)	6.7 (1)	
	Consultation service	65.6 (21)	15.6 (5)	86.7 (13)	13.3 (2)	
	Contact to hospice care services	81.3 (26)	9.1 (3)	80.0 (12)	13.3 (2)	

^aItems attaining consensus (at least 75%) in bold.

^bGerman Hospice and Palliative Care Evaluation (HOPE) is a national, long-term quality assurance project. Every year German hospice and palliative care institutions document a core data set for their patients covering a 3-month period. The HOPE Symptom and Problem Checklist includes items on physical, nursing, psychological, and social symptoms and problems.

MS, multiple sclerosis; EDSS, Expanded Disability Status Scale.

Table 4 sums up criteria found so far within our Delphi study and expert workshop as well as in the above mentioned studies^{12,13,27} for integrating specialized palliative care in MS.

Discussion

This study attained consensus from German health care professionals on criteria regarding when and why palliative care could be integrated into routine care of MS. This adds to our own results from studies with severely affected patients^{2,7,9} where we found initial indications that palliative care could be a valuable, complementary asset to improve fatigue, pain, physical dysfunctions, and offering psychosocial support. The descriptive criteria supplements recent in-

terventional studies from the United Kingdom^{12,13,27} where integration of palliative care services led to improvement of symptoms such as pain, nausea, vomiting, mouth problems, and sleeping. Combining the United Kingdom results with our consensus items may enable the development of a first set of criteria for Germany indicating when physicians should consider integrating palliative care services, and thereby facilitate future interventional research on severely affected MS patients.

Palliative care for MS: When?

Experts have suggested that patients with MS may benefit from specialized PC when the disease has progressed

TABLE 4. LIST OF POSSIBLE CRITERIA FOR INTEGRATING SPECIALIZED PALLIATIVE CARE IN MULTIPLE SCLEROSIS

Possible criteria for integrating specialized palliative care in MS

EDSS > 6	Consensus attained
Need for nursing care	within this Delphi study
Psychosocial support	
Support for relatives	
Communication on disease progression	
Pain medication	
Symptom control	
EDSS ≥ 8.0	Suggested from experts
Two symptoms on the HOPE-Scale ¹⁴ (0–3) scoring 3	in workshop
Decreasing cruising radius	
The need for moving into a nursing care home or admission to a hospital	
EDSS > 8.0	Suggested by the
Nausea	U.K. team ^{12,13,27}
Vomiting	
Pain	
Mouth problems	
Sleeping	
Relieve caregiver burden	

MS, multiple sclerosis; EDSS, Expanded Disability Status Scale; HOPE, Hospice and Palliative Care Evaluation.

(Expanded Disability Status Scale [EDSS]^b > 6 and nursing care required), when there is a need for nursing care, when distressing symptoms such as pain appear, or when there is a need to communicate about the disease and its progression. Workshop participants discussed different criteria for the integration of specialized PC in MS such as EDSS ≥ 8.0 and/or relapse (Table 3).

Workshop experts differ on this from our Delphi participants who thought that PC should not be integrated when there is a relapse. Depending on the form of MS, not all relapses lead to worsening disabilities, but may be temporary and later regress.

In the European Multiple Sclerosis Platform (EMSP) Toolkit on Code of Good Practice²⁸ the key clinical indications for when a referral for assessment or to a specialized palliative care service is beneficial were significant and complex symptoms (e.g., pain or nausea); the need for advance care planning; support in end-of-life decision-making and assessment of capacity regarding decision making. Our results validate these, and offer further indications.

The above mentioned study by Leray et al.¹ showed that the duration of phase 2 (from DSS 3 to 6) was nearly identical

among patients regardless of the duration of phase 1. Palliative care could be a valuable asset in this later phase since the disability progression continues and cannot be influenced causally.

Oncology has coined the term “early integration” in the discussion about the right time to implement PC specialists in palliative care. Here, green flags and red flags have been devised to develop standard operating procedures for an early integration approach.²⁹ Temel et al.³⁰ were able to show that early palliative care led to significant improvements in both quality of life and mood in addition to prolonging life. That participants in our study see the integration as rather late in the disease trajectory might illustrate how misperceptions still exist and how a lack of information regarding palliative care, as identified earlier,^{9,31} remains. Similar, formalized approaches will have to be developed for neurologic disorders such as MS.³² Otherwise, the individual patient will depend too much on the physician having to recognize unmet palliative care needs or not. This seems to be rather difficult since workshop experts mentioned their uneasiness about informing patients about palliative care services, making it that much more important to have good patient information and education.

Delphi participants revealed that they did not believe palliative care should be integrated for alleviating depression. This might point to some indecision on the part of neurologic health professionals regarding palliative offers and expertise, as depression is a relevant issue for palliative care, specifically in terms of identifying “normal” grief versus depression or psychopathologic grief.

Health care professionals tend to view palliative care as an option when there is nothing more that can be done for the patient, rather than seeing it as something additional to be delivered simultaneously with treatments focused on the disease.³³ A survey of physicians¹⁵ found much resistance in viewing palliative care as other than “hospice” or “end of life.” Health care professionals need to recognize the benefits of palliative care and communicate these benefits to both patients and their families.³⁴

Palliative care for MS: Why?

Palliative care services have traditionally focused on caring for patients with cancer. The symptom burden experienced in progressive neurologic conditions like MS has much in common with that of cancer, suggesting that palliative care services might have a role here as well.³⁵ Our results show consensus on palliative care offers that should prove beneficial when treating severely affected MS patients, i.e., psychological support, support for family and caregivers, outpatient care, consultation services, and when contacting hospice care services. There is also consensus that palliative care should be integrated when there is a need for pain medication, since pain syndromes are common to MS. According to the National MS Society, 55% of people with MS had “clinically significant pain” at some time. Almost half (48%) were troubled by chronic pain (www.nationalmssociety.org). Health care professionals in our study also indicated the importance of stepping up outpatient care and psychosocial services in the field for palliative care. A recent study on integrating palliative care into the outpatient, private practice setting (in the field of oncology) confirmed that this reduces patients’ symptom burden.³⁶

^bThe EDSS is a method for quantifying MS level of disability and for monitoring changes in the level of disability over time. It is widely used in clinical trials and in the assessment of patients with MS. The scale was developed by the neurologist John Kurtzke in 1983 as an improvement to his previous 10-step Disability Status Scale (DSS). The EDSS scale extends from 0 (normal neurologic examination) to 10 (death from MS complications) in increments of 0.5 units. Scoring is based on an examination by a neurologist.

Palliative care for MS is still limited partially due to the lack of models available. Higginson et al.¹³ initially developed and evaluated a new palliative care service for people severely affected by MS (both people with MS and their families/caregivers), closely linked to an established MS service run by neurologists and MS nurses. Five main concerns for patients and families were identified: loss and change, support needs, information needs, symptom control, and issues concerned with the delivery of care including coordination, continuity, and problems with inpatient care.¹³ Our studies² also found that in addition to the physical burden, other factors likely contribute to severe affectedness, namely difficult psychosocial circumstances, social isolation as well as losses and changes in independence, relationships, and social roles.

These results again show the high importance of multidisciplinary care for patients severely affected by MS and also highlight the importance of specialized palliative care.

Patients severely affected by MS have an interest in communicating about issues concerning death and dying especially because of the severity of their problems as well as the progressive nature of severe MS.⁷ Palliative care integration should be considered when communication about the progression of the disease and advance care planning are necessary.

Several aspects found consensus among the workshop experts participating in our Delphi study, including deficient home care services as well as the lack of knowledge about PC services or the disease itself by certain institutions caring for MS patients. Workshop participants also mentioned that PC itself often lacks specific knowledge about MS, its management and treatment, indicating that PC might benefit through learning from other medical fields as well. The recommendations that emerged from the workshop demonstrate the value of close interaction between different professions.

Strengths and limitations of the study

A pilot test and feedback on the preliminary questionnaire were utilized to ensure the validity and reliability of the survey instrument. Our Delphi panel included multi-professional experts in the field of MS, and the high degree of consensus among this group further supports the validity of our findings.

Through an extensive online search, many experts, with whom we had no previous contact, were invited, with perhaps a higher risk of refusal. Attempts were made to increase participation through the use of incentives (book coupons), the low response rate in round 2 presents a limitation. Thus, our results must be seen in light of this restriction even if opinions on nonresponse bias and recommendations for acceptable dropout rates vary³⁷ and “the response bias may not be nearly as serious for small samples as it is for large samples.”³⁸ In addition, generalizability of consensus on the broad range of issues identified is limited, as participants were only recruited in the Cologne/Bonn area (Germany).

As the Delphi group consisted of experts caring for, on average, only a small number of severely affected patients, it need be mentioned that there is the potential for some discrepancy with respect to what constitutes an expert for these purposes. Thus, it may be inaccurate to classify all participants as highly experienced professionals *per se*. Despite

self-ratings of our own expertise as “rather high” to “high” (60.2% [round 1] and 60.0% [round 2]), their views offered may be regarded more as the current opinions of mostly, moderately experienced health care professionals, rather than expert opinion to be seen as future recommendations.

Perhaps the limited number of patients seen reflects the nature of the health care system, whereby many severely affected MS patients seem to become obscured or lost.³⁹ Perhaps the low number of patients being treated by our experts is not a good indicator of MS patients severely affected by MS as they cannot reach these patients and vice versa. At least in Germany, there is a lack of epidemiologic data about those patients most severely affected by MS (where they live, who cares for them, etc.) and home visits are insufficiently funded by the national health care system.

Conclusion

Our results clearly identified specific areas where PC will likely prove to be a valuable asset in the treatment course of MS, expanding upon those identified by the U.K. team^{12,35} where integrating palliative care led to a reduced burden of patient symptoms and some beneficial aspects for caregivers.

For some diseases identifying the “when” and “why” of palliative care utilization can appear intuitive (eventually standardized for diseases such as cancer⁴⁰), however identifying “signposts” for MS remains challenging, mainly because of patient symptomatic complexity and heterogeneity.²⁸ Obtaining consensus among accomplished experts on criteria for palliative care integration outlines initial guidelines for specifying palliative care assignments and infrastructure. Once these criteria are further investigated and validated in future research, formalized approaches can be developed for neurologic diseases equal to those already existing for oncologic diseases.

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